

One Hundred Eighth Congress
of the
United States of America

AT THE FIRST SESSION

*Begun and held at the City of Washington on Tuesday,
the seventh day of January, two thousand and three*

An Act

To revise and extend the Birth Defects Prevention Act of 1998.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the “Birth Defects and Developmental Disabilities Prevention Act of 2003”.

SEC. 2. NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES.

Section 317C of the Public Health Service Act (42 U.S.C. 247b–4) is amended—

(1) in subsection (a)(2)—

(A) in subparagraph (A)—

(i) by striking “and developmental disabilities” and inserting “, developmental disabilities, and disabilities and health”; and

(ii) by striking “subsection (d)(2)” and inserting “subsection (c)(2)”;

(B) in subparagraph (B), by striking “and” at the end;

(C) in subparagraph (C), by striking the period and inserting a semicolon; and

(D) by adding at the end the following:

“(D) to conduct research on and to promote the prevention of such defects and disabilities, and secondary health conditions among individuals with disabilities; and

“(E) to support a National Spina Bifida Program to prevent and reduce suffering from the Nation’s most common permanently disabling birth defect.”;

(2) by striking subsection (b);

(3) in subsection (d)—

(A) by striking paragraph (1) and inserting the following:

“(1) contains information regarding the incidence and prevalence of birth defects, developmental disabilities, and the health status of individuals with disabilities and the extent to which these conditions have contributed to the incidence and prevalence of infant mortality and affected quality of life;”;

(B) in paragraph (3), by inserting “, developmental disabilities, and secondary health conditions among individuals with disabilities” after “defects”;

(C) in paragraph (4), by striking “and” at the end;

(D) by redesignating paragraph (5) as paragraph (7);
and

(E) by inserting after paragraph (4) the following:

“(5) contains information on the incidence and prevalence of individuals living with birth defects and disabilities or developmental disabilities, information on the health status of individuals with disabilities, information on any health disparities experienced by such individuals, and recommendations for improving the health and wellness and quality of life of such individuals;

“(6) contains a summary of recommendations from all birth defects research conferences sponsored by the Centers for Disease Control and Prevention, including conferences related to spina bifida; and”;

(4) by redesignating subsections (c), (d), and (e) as subsections (b), (c), and (d), respectively;

(5) by inserting after subsection (d) (as so redesignated), the following:

“(e) **ADVISORY COMMITTEE.**—Notwithstanding any other provision of law, the members of the advisory committee appointed by the Director of the National Center for Environmental Health that have expertise in birth defects, developmental disabilities, and disabilities and health shall be transferred to and shall advise the National Center on Birth Defects and Developmental Disabilities effective on the date of enactment of the Birth Defects and Developmental Disabilities Prevention Act of 2003.”; and

(6) in subsection (f), by striking “\$30,000,000” and all that follows and inserting “such sums as may be necessary for each of fiscal years 2003 through 2007.”.

SEC. 3. TECHNICAL CORRECTIONS FOR STATE COUNCILS ON DEVELOPMENTAL DISABILITIES.

(a) **IN GENERAL.**—Section 122(a) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15022(a)) is amended—

(1) in paragraph (3)(A)(ii), by inserting before the period the following: “, the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater”; and

(2) in paragraph (4)(A)(ii), by inserting before the period the following: “, the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater”.

(b) **EFFECTIVE DATE.**—The amendments made by subsection (a) shall take effect on October 1, 2003 and apply to allotments beginning in fiscal year 2004.

SEC. 4. REPORT ON SURVEILLANCE ACTIVITIES.

Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services jointly with the Secretary of Education shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce and Committee on Education and the Workforce of the House of Representatives a report concerning surveillance activities under section 102 of the Children’s Health Act of 2000 (Public Law 106–310), specifically including—

(1) a description of the current grantees under the National Autism and Pervasive Developmental Disabilities Surveillance Program and the Centers of Excellence in Autism and Pervasive Developmental Disabilities, the data collected, analyzed, and

reported under such grants, the sources of such data, and whether such data was obtained with parental consent as required under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. 1232g);

(2) a description of current sources of data for the surveillance of autism and developmental disabilities and the methods for obtaining such data, including whether such data was obtained with parental or patient consent for disclosure;

(3) an analysis of research on autism and developmental disabilities with respect to the methods of collection and reporting, including whether such research was obtained with parental or patient consent for disclosure;

(4) an analysis of the need to add education records in the surveillance of autism and other developmental disabilities, including the methodological and medical necessity for such records and the rights of parents and patients in the use of education records (in accordance with the Family Educational Rights and Privacy Act of 1974);

(5) a description of the efforts taken by the Centers for Disease Control and Prevention to utilize education records in conducting the surveillance program while obtaining parental or patient consent for such education records, including the outcomes of such efforts;

(6) a description of the challenges provided to obtaining education records (in the absence of parental or patient consent) for the purpose of obtaining additional surveillance data for autism and other developmental disabilities; and

(7) a description of the manner in which such challenges can be overcome, including efforts to educate parents, increase confidence in the privacy of the surveillance program, and increase the rate of parental or patient consent, and including specific quantitative and qualitative justifications for any recommendations for changes to existing statutory authority, including the Family Educational Rights and Privacy Act of 1974.

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*